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FORUM ON HEALTH AND NATIONAL SECURITY

# STIGMA AND BARRIERS TO CARE CARING FOR THOSE EXPOSED TO WAR, DISASTER AND TERRORISM

## EXECUTIVE SUMMARY AND RECOMMENDATIONS

Center for the Study of Traumatic Stress  
Department of Psychiatry  
Uniformed Services University of the Health Sciences  
and Defense Centers of Excellence







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FORUM ON HEALTH AND NATIONAL SECURITY

STIGMA AND BARRIERS TO CARE  
CARING FOR THOSE EXPOSED TO WAR,  
DISASTER AND TERRORISM

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STIGMA AND BARRIERS TO CARE  
CARING FOR THOSE EXPOSED TO WAR, DISASTER AND TERRORISM

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First Edition

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## PREFACE

This Forum on Health and National Security, directed to addressing stigma and barriers to care, brought together a diverse group of leaders in order to expand our horizons on these issues of important national need in times of war, disaster and terrorism. The individuals represented national leaders, educators, researchers and health care planners across mental health, health care systems, military and disaster care and the specific issues of stigma and barriers to care. Our goal was for individuals who did not usually talk with each other or even know of each other's work, to hear new perspectives and create a new vantage point on this difficult topic. We operated under the belief that if one only talks to people that you already know we cannot maximize our joint knowledge and opportunities. We hoped that those in attendance would leave with at least two new names of people who would be helpful and of interest in pursuing our needs to address stigma and barriers to care.

Our primary goal was to better understand the issues of stigma and barriers to care as they relate to the trajectory from illness, distress and health risk behaviors after war, disaster or terrorism to care and needed help. At that point the group could translate their understanding into action through recommendations. The work of the Forum was a series of presentations followed by thinking together. Our final discussions were to formulate a set of recommendations to capture the ideas generated. The recommendations were organized into the areas of research, education and training, leadership and intervention. We hope this volume communicates the important ideas and recommended actions from this distinguished group.

*Our primary goal was to better understand the issues of stigma and barriers to care as they relate to the trajectory from illness, distress and health risk behaviors after war, disaster or terrorism to care and needed help.*





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## EXECUTIVE SUMMARY AND RECOMMENDATIONS

What is stigma? What is it that prevents people from getting help for psychological and behavioral problems after war, disasters or terrorism when they need it? What are the predictors of not coming for care and assistance? Is it because one would feel embarrassed? Is it because of inadequate transportation? Or that a person cannot get an appointment? Or are there other factors such as lack of trust in mental health professionals or people thinking treatment is not going to work, or believing “I can handle it myself”?

The Forum on Health and National Security is a conference series addressing the intersection of health and national security needs. The goal of this first conference was to better understand stigma and barriers to care in those exposed to war, disaster and terrorism and to translate that understanding into action. Stigma is associated with behavioral health in general and emergency behavioral health in particular. To address stigma and barriers to care it is important to address the marginalization and misunderstanding about what we can and cannot do in mental health and the myths about our field. Mental health stigma is not just about getting treatment. It is an attribute of many aspects of behaviors, including health and illness, and it is a part of our social interactions. It disqualifies individuals from a particular group citizenship. It can negate acceptance in the family sphere and the work place.

There are other reasons which also play a part in why people do not come forward for treatment. Perhaps most importantly if they believe that we are offering them treatment for something they do not see as a problem. Similarly, as care providers we like diagnoses — they orient our treatments and give us guideposts — but people who have illnesses do not always like them. People do not like to be placed into the ‘abnormal’ category. For mental health diagnoses, both in the military or civilian worlds, how to modify societal beliefs that psychiatric and psychological problems mean weakness is a major challenge.

Looked at from the other side of stigma— what are its consequences? What are the behavioral implications of stigma? Over the years there have been a number of efforts by community mental health to educate neighborhoods about mental health and illness. Often these messages have been that mental illness is not really an illness and not really dangerous. What researchers have discovered is that when we provide education to the community it may only help the neighborhood mobilize against those with behavioral and health problems more quickly. People who have behav-

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ioral and health problems “know” that other people feel awkward around them. Therefore people often are reluctant to go for treatment. This is particularly true in the armed forces where the ethos is, “I don’t need help. I can handle things myself.”

There is good reason to think that embarrassment is an important cause of failure to get treatment and an important cause of dropping out of treatment prematurely. This embarrassment is based in part on the perception of the stigma associated with emotional disorders, the idea that it is shameful to have a mental illness and that it is a character flaw. The General Social Survey (GSS) conducted by the National Opinion Research Center, University of Chicago, has been monitoring attitudes about mental illness since 1972 and has documented an increase in the perception that mental illness is attributable to biological causes rather than a character flaw. There has been an increase in the perception that biological treatment is likely to be the most effective kind of treatment. Part of the reason for this is that there has been a massive increase in public information about mental illness since the early 1990’s. However, it is not always true that giving people more information creates the behavioral changes desired. Now the perception that one’s family may carry dangerous genes has become part of the stigma burden.

Mental health includes resilience as well as disorders, distress responses, and health risk behaviors. How do barriers to care affect each of these? Distress responses can also be thought of as subthreshold mild to moderate symptoms and often are early signs indicating the need for treatment or psychological rest. They also impair performance. We need to particularly better understand how barriers to care can impact the performance and health of individual service members, public health responders and other safety and security personnel as well as their organizations. It is important to address the individual’s impairment of function and how barriers to care also lead to increased disability. Complicating the issues is the fact that disability may increase with the award of compensation.

Health risk behaviors, e.g., use of cigarettes, changes in use of alcohol, accidents in particular road traffic accidents, and substance abuse, are a part of the health burden after war and disasters. They are too often overlooked in the broader public health issues after traumatic events. These are important targets for prevention and intervention in which stigma and barriers to care also impact health trajectories. For example, altering cigarette use substantially alters morbidity and mortality related to disease. In addition it is a part of the health environment of our families and our service members. We know cigarette use changes after exposures to combat, disasters, and terrorism. Our 18–25 year-olds are those who have the highest rates of cigarette use.

The individual’s perception of the need for care is an important part of the trajectory from illness, distress or health risk behaviors to care. About 17% of DoD reported a need for counseling. Approximately 4.8% of DoD has received a medication for depression, anxiety, or sleep; 14.6% have received some type of mental health counseling. Half of the counseling is from a military mental health professional. Importantly, approximately 44% describe probable or definite perceived damage to their career for seeking mental health counseling. Sorry to say but true is that this is similar for the nation as a whole. In 2004 Hoge et al. found that considerably more than half of the soldiers and marines who were surveyed and seemed to be in need of treatment, indicated that they had not received any treatment. Stigma and barriers to care were an important component in their path to care.

Families also have particular problems during war and disasters and concern

about stigma in families can prevent care to children and family members. For example, there are barriers to care related to intervention for family conflict and child neglect. We need to consider outreach to these populations. How to alter the system to better reach them and they reach us? Somatic symptom reporting is particularly important to the health care system. Unexplained and idiopathic somatic complaints increase in times of war and disasters also as shown following Katrina or in New York City after 2001. Somatic symptoms complaints raise issues of stigma and barriers to reaching the correct care, and the overtreatment of people who may not need physical health care.

In considering recommendations to address stigma and barriers to care as an impediment in the illness to treatment path, there are several models to consider. One approach is the traditional primary, secondary, and tertiary prevention. This involves response and prevention of disability. Another approach follows the IOM suggestions from 1994 which address whether an intervention is for the entire population or high risk groups. In addition, for war, disaster, and terrorism — similar to the Haddon Matrix — there are stages to consider: pre-stage, an event stage in which we operate, and a post-event stage.

How do we place disaster response, war and terrorism in these frames of reference to better address barriers and stigma? These are the issues addressed by the distinguished group of speakers and participants in this Forum on Health and National Security. Our recommendations inform and direct thoughts for research, training and education, leadership and intervention to best address stigma and barriers to care of our service members, their families and our nation as a whole in times of war, disaster and terrorism. The following summarizes the recommendations of the group.

## Research Directions

1. The stigma associated with psychological health has changed little since the start of the war despite massive education and screening campaigns. It is conceivable that the stigmatization process as a means of differentiating “in” and “out” groups plays such a central role in maintaining performance that changing the culture will continue to be a long-term goal. In order to mitigate the health and national security implications of such a phenomenon research is needed to develop alternative approaches to care. Areas for exploration include the study of the effects of relationships on altering barriers to care, coaching models of care, processes of effective care, case definition and identification, and referral and access to health care. The role of buddy care and mechanisms for fostering connection with others and support require further study.
  - Develop alternatives to diagnosis and disability-based models of care.
  - Examine the effects of buddy, leadership, and family relationships on barriers to care.
  - Examine the effectiveness of coaching models of care in decreasing barriers to care.
  - Examine the process of reaching care from case identification to referral to access.
  - Examine the role of buddy care and psychological first aid in altering barriers to care.

*The stigma associated with psychological health has changed little since the start of the war despite massive education and screening campaigns.*



*Many factors, including stigma, inhibit symptomatic individuals from seeking care following exposure to disaster, war, and terrorism.*

- Identify the role of self-help groups in promoting care seeking and adherence.
  - Examine the mechanisms of fostering connections with others as a factor in altering stigma and interpersonal barriers to care.
2. Many factors, including stigma, inhibit symptomatic individuals from seeking care following exposure to disaster, war, and terrorism. Of those who are brought to clinical attention many drop out or receive inadequate care. Research is needed to better understand vocational trajectories after care seeking, the positive effects of treatment, the process of reaching effective care, and the effectiveness of contact at various stages from symptom onset to impairment across outcomes. These outcomes include distress, disorder, health risk behaviors, and injury. There is a paucity of qualitative study of the narratives of injured soldiers who successfully negotiated barriers to care including stigma, received treatment, remained in treatment, and shared their experience of effective care. There is a need for case control or cohort studies of “declining care” with outcome variables including job function, home function, health and resilience.
    - Identify vocational trajectories after care seeking including the positive effects of treatment.
    - Examine the impact of contact across stages of psychological and behavioral responses to traumatic events on the trajectory of care seeking.
    - Use qualitative techniques to examine the narratives of trauma survivors.
    - Conduct studies of the effects of declining care across various outcomes.
  3. Research is needed to understand, develop, and make accessible high-quality, practical, evidence-based care for symptomatic individuals exposed to disaster, war, and terrorism. We need to better understand how to get rapid relief for those who enter primary or specialty care. Research is needed to examine what is effective in therapy and how to optimize primary care settings to identify and treat mental health disorders in less stigmatized settings in a manner which does not burden the primary care practitioner. We need to better understand what happens in psychotherapy in order to encourage participation in specialty care. Studies are needed to examine technologies used to get patients to treatment, get treatment to patients and to provide information and treatment in less stigmatizing settings.
    - Further develop high-quality, practical, evidence-based care for symptomatic individuals exposed to trauma.
    - Identify treatments that provide rapid and sustained relief and methods of delivery that decrease stigma and barriers.
    - Identify ways to optimize collaborative care in the primary care setting.
    - Develop qualitative methods to examine the narratives of successful treatment across the trajectories of accessing care.
    - Examine technologies to get patients into treatment that present information and treatment in less stigmatizing settings.
  4. Screening programs such as Post-Deployment Health Assessment (PDHA) and Reassessment (PDHRA) should be examined for positive and negative predictive



value, cost-effectiveness, and unintended consequences. For example, universal face-to-face mental health screening of all redeploying soldiers is difficult to implement and can deplete already overwhelmed treatment resources. In addition it may exacerbate patient concerns about confidentiality and decision-making autonomy. Selective Primary Care Screening for Depression and PTSD, as implemented in the Re-Engineering Systems of Primary Care Treatment in the Military (RESPECT-MIL) program sets the standard for optimizing access to primary health care while minimizing the potential for stigmatization associated with health care utilization. Internet-based interventions designed to get people into treatment need further development, broader implementation, and an evaluation strategy. Research is needed to evaluate the collaboration between the primary care and mental health communities in order to optimize collaboration.

- Study positive and negative predictive value, cost-effectiveness, and potential unintended consequences of PDHA, PDHRA.
- Study the unintended consequences of mandatory face-to-face mental health screening for all redeploying soldiers, irrespective of risk stratification.
- Continue implementation and evaluation of RESPECT-MIL program.
- Develop, implement and evaluate the effectiveness of internet-based interventions.
- Evaluate the collaboration between the primary care and mental health care communities' considerations in order to optimize collaboration.
- Examine the trajectory of post-traumatic reactions, including recovery, disability, and impairment.
- Examine the effects of co-morbid medical illness on barriers to care and stigma.
- Identify factors that initiate and perpetuate the illness role.

### Training and Education

Initial and refresher training and education of primary and specialty care providers for encouraging service members and disaster exposed families and public health workers to enter care (e.g. motivational interviewing) are important for optimal treatment strategies, programs and goals. Individuals seeking assistance need to be directed to high quality easily accessible information. A clearinghouse to establish and maintain sources of information is needed. Military leadership education and training at all ranks should include education on barriers to care (including stigma), and help seeking as an element of the service's core values and on various cultural "languages" acceptable to care seeking. In keeping with a "safety culture/safety climate" emphasis, help seeking as a means of performance optimization and training on recognizing evidence of distress should be included as an element of such curricula. It is important to maximize the extent to which this training can be provided by unit leaders to forward unit mental health providers. Leadership mastery of skills should be tested and rewarded, offering badges or special skill identifiers analogous to the Combat Lifesaver designation as potential reinforcements for soldiers developing expertise in this area. Vocational rehabilitation should be included as an element of performance enhancement. It is important to optimize, disseminate, and

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evaluate web-based treatments for PTSD and to identify ways to inform the use of testimonials as evidence of effective care. Training in non-health care settings such as communities, work places, and jails should be provided.

- Provide initial and refresher training and education of primary care and specialty care providers in optimally motivating patients to seek care as well as treatment strategies, programs and goals.
- Direct individuals seeking assistance to high quality, easily accessible information. Establish and maintain a clearinghouse of sources of accurate information.
- Establish military leadership education and training at all ranks to include education on barriers to care (including stigma), and promoting help seeking as an element of each service's core values. This should include training on recognition of signs of distress in self and others, normalization of work-rest cycles. The DCoE Real Warriors program is an excellent example.
- Reframe help seeking as a means of performance optimization and include training on recognizing signs of distress in oneself and others.
- Promote vocational rehabilitation as an aspect of performance enhancement.
- Optimize, disseminate, and evaluate web-based treatments for PTSD.
- Use individual testimonials to highlight the availability of effective care.
- Include non-health care personnel and settings in training and education.
- Study the science and processes of training in order to optimize effectiveness.

### **Leadership**

Public mental health and military mental health leadership need to integrate the message of help seeking as an aspect of performance enhancement and organizational development. Leaders should incorporate a blend of behavioral health prevention and improving capacity for evidence based service delivery in their organizations. Military leaders should integrate evidence based interventions into training and implement this at the level of operational units. Leaders need to reinforce the value of recognizing signs of distress, along with endorsing and underwriting a cultural shift toward rest and "taking a knee" when indicated. Structural efforts should be directed at improving confidentiality associated with care seeking. When highly effective treatments are available and accessible leaders need to articulate their support for care seeking and aid in dispelling myths about what happens in treatment.

- Consider a conference to expand the focus of this discussion to the broader national public mental health agenda to provide strategies and vision on behavioral public health of the nation.
- Integrate the message of help seeking as performance enhancement into all levels of leadership education and training, and policy making.
- Train leaders to incorporate a balanced blend of behavioral health prevention and improving capacity for evidence based service delivery.
- Ensure that evidence based interventions are integrated into training and implemented at the level of operational units.

- Reinforce the importance of recognizing signs of distress, along with endorsing and underwriting a cultural shift toward rest and “taking a knee” when indicated.
- Continue structural efforts toward improving confidentiality associated with care seeking.
- Leaders must be able and willing to articulate their support for care seeking, and aid in dispelling myths about what happens in treatment and after treatment is sought.
- As a preventive measure, policy makers and leaders should continue to improve deployment to dwell time ratios for military personnel.

*Many excellent programs for stigma mitigation designed to reduce barriers to care exist in the Department of Defense, Department of Veterans Affairs and civilian public health and academic centers.*

### Intervention

Many excellent programs for stigma mitigation designed to reduce barriers to care exist in the Department of Defense, Department of Veterans Affairs and civilian public health and academic centers. Leaders should foster and support ongoing evaluation of these program interventions using measurable and operational outcomes. We must consider how non-health care systems can be leveraged to reduce stigma and other barriers to care spanning the contexts of war, terrorism and disaster. Appealing to altruism, enlisting others to provide support has been an important guiding principle in the British TRIM program. Evidence informed frameworks such as Psychological First Aid should guide targeted interventions. Effective public health planning tools, such as the Haddon Matrix, can be helpful in designing phased programs. It is important to optimize the use of self-help groups to promote treatment adherence. Programs such as the DCoE Real Warriors, Bryan Doerries Theatre of War, and social media such as Twitter or Facebook are examples of creative interventions to promote “contact”, widely regarded as the most critical element of successful stigma mitigation effort. Mental health should collaborate with marketing and media experts to establish long-term public behavioral health educational campaigns and to promote collaboration between civilian and military communities.

- Leaders should foster and support ongoing evaluation of programmed interventions using measurable and operational outcomes.
- Non-health care systems can be leveraged to reduce stigma and other barriers to care in the context of war, terrorism and disaster.
- Evidence informed frameworks such as Psychological First Aid should guide targeted interventions.
- Effective public health planning tools, such as the Haddon Matrix, can be used to design public health programs.
- Self-help groups, which are known to promote treatment adherence should be optimized.
- Programs such as the DCoE Real Warriors, Bryan Doerries’s Theatre of War, and social media such as Twitter or Facebook are examples of creative interventions to promote “contact”, widely regarded as the most critical element of successful stigma mitigation efforts.

- Collaborate with marketing and media experts in establishing long-term public behavioral health educational campaigns.
- Promote collaboration between civilian and military communities.



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